

## Polio Australia Incorporated

Representing polio survivors throughout Australia



## e-Bulletin

## **April Reflections 2011**

April was a very busy and exciting month for Polio Australia as we facilitated our second and very successful Polio Health and Wellness Retreat in the picturesque Victorian bayside town of Mt Eliza. More details can be found on page 4 of this e-Bulletin. As a follow up to last month's request by Post-Polio Health International (PHI) to assist members of the Japanese polio community in the wake of the earthquake and tsunami destruction, we were advised that PHI had received donations totaling 359,693 yen (\$4,500), together with a heartfelt message from Kazuhiko Abe, Director of Sendai Polio Society, Japan.

> "One of the secrets of inner peace is the practice of compassion." Tenzin Gyatso, The 14th Dalai Lama

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## **National Disability Strategy**



The National Disability Strategy sets out a ten year national plan for improving life for Australians with disability, their families and carers. It represents a commitment by all levels of government, industry and the community to a unified, national approach to policy and program development. This new approach will assist in addressing the challenges faced by people with disability, both now and into the future.

The Strategy sets out six priority areas for action to improve the lives of people with disabilities, their families and carers. These are:

- 1. Inclusive and accessible communities
- 3. Economic security
- 5. Learning and skills

- 2. Rights protection, justice and legislation
- 4. Personal and community support
- 6. Health and wellbeing

Read more here

#### **Easier Access to Navigate Aged Care System**

Press Release: The Hon Mark Butler, MP — Minister for Mental Health and Ageing 5 April 2011

From 1 July 2011, older Australians and their carers will find it easier to access and navigate the aged care system with the introduction of a single phone number to access and navigate the system as the first step in the phased implementation of the one-stop shop measure. Click here to view the full media release.

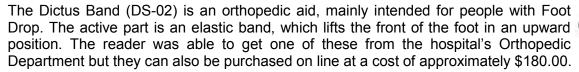
#### Therapeutic Goods Administration (TGA) Launches New Website

Press Release: The Hon Catherine King, MP — Parliamentary Secretary for Health and Ageing and Parliamentary Secretary for Infrastructure and Transport 4 May 2011

The Australian community's access to authoritative information about the safety of medicines and medical devices will be greatly enhanced with the launch today of a revamped Therapeutic Goods Administration (TGA) website. Click here to view the full media release or go directly to www.tga.gov.au

#### **Dictus Band - DS-02**

As printed in PolioWA's March 2011 newsletter, one of the readers was sharing her positive experience with an orthopedic aid called the <u>Dictus Band</u> made by Erimed of Sweden.





### A vaccine 'revolution' aims for safer, cheaper treatments

By Maureen, FierceBiotech May 5, 2011



An innovative way of making vaccines at the University of Central Florida has attracted the support of the Bill & Melinda Gates Foundation for its potential to make vaccines less expensive, more effective and needle free.

Since 2000, UCF Professor Henry Daniell has been developing a new method of creating vaccines using genetically engineered tobacco and lettuce plants to fight diseases like malaria, cholera, dengue or biothreat agents like anthrax or plaque.

This month, the <u>Gates Foundation</u> awarded Daniell a two-year \$761,302 grant to develop a polio vaccine. Konstantin Chumakov, associate director, Center for Biologics Evaluation and Research at the Food and Drug Administration, is a collaborator in the grant and will facilitate advancement of this novel technology.

Should Daniell's vaccine receive FDA approval, it would open the door for the production of a variety of cheaper, more effective vaccines around the world.

"If this proceeds as we expect, it will revolutionize how vaccines are made," Daniell said. "We're currently using decades-old technology that is expensive and inefficient. Our new process is a game changer that could make a global difference." Read the <u>full article here</u>.

#### \$100,000 grant for polio research

By Isha Flores, The Dartmouth Staff (UK) May 4, 2011

Researchers at Dartmouth Medical School (DMS) received an 18-month \$100,000 Grand Challenges Explorations grant to examine the way polio vaccines work in resource-limited countries with high population densities and poor sanitation, according to DMS pediatrics professor Peter Wright. The DMS team, led by Wright, received the Bill and Melinda Gates Foundation-sponsored grant for a project titled "Mucosal Immunity in Polio" on Thursday.

Out of over 2,500 applications submitted to the Grand Challenges Explorations initiative this year, 88 projects from around the world were selected to receive funding, according to Katie Harris from the communications department of the Gates Foundation. Winners are announced twice a year, and the number of selected teams ranges from 70 to 88, Harris said.

"I have a long-standing interest in polio, and we're in the middle of a long a difficult effort to eradicate polio," Wright said. "One of the key questions is how one is protected against polio, getting polio and spreading polio to others in areas with a high risk of infection." Read the full article here.

#### Polio this week

Source: Polio Global Eradication Initiative

Total cases	Year-to-date 2011	Year-to-date 2010	Total in 2010*
Globally	123	115	1291
in endemic countries:	43	44	232
in non-endemic countries:	80	71	1059

#### **PolioPlace People of Note**

Many of Australia's Victorian polio survivors will have experienced "Dame Jean's" ministrations in their younger years. She is now being featured on PHI's PolioPlace website for the rest of the world to appreciate.

Dame Annie Jean Macnamara, MD

**Born:** April 1, 1899 Died: October 13, 1968

#### **Major Contribution**

An Australian medical doctor and scientist, Dame Annie Jean Macnamara (later Connor) was best known for her contributions as a consultant and medical officer to the Poliomyelitis Committee of Victoria 1925-31. During the 1937-38 polio epidemic, she worked with Frank Macfarlane Burnet (who later won a Nobel Prize for medicine) to discover that there was more than one type of polio virus (British Journal of Experimental Pathology, 1931).

#### Have you referred your adult children to PHI's new publication?



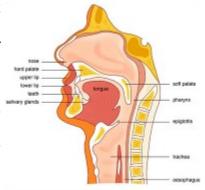
A PHI Member sent this note: "Thank you for the excellent publication, Post-Polio Health Care Considerations for Families and Friends. I printed it off just last night and found it to be very informative. Sometimes, I think I have it all together, but lately I've been having to accept that my body

continues to change. The information you've provided was a good reminder of both what to be aware of as well as best practices."

#### **Swallowing Difficulties**

One of the Facilitators at Polio Australia's Health and Wellness Retreat in Mt Eliza was Abby Foster, a Speech Pathologist from St Vincent's Hospital, Melbourne. Abby spoke about the fact that difficulty with swallowing dysphagia — is not an uncommon problem for people who have had polio. She also advised participants to take the time to become familiar with their own swallowing patterns, and to know the signs for when to seek help.

The discussion that followed revealed that swallowing difficulties were actually impacting quite substantially on many people's lives. The participants revealed that they now avoid social interaction which might include eating because they are too embarrassed about the possible consequences. This distressing situation can make people feel quite isolated.



It is most important that people experiencing these problems get a proper assessment by a Speech Pathologist to explore appropriate management strategies. Visit www.speechpathologyaustralia.org.au to find a Speech Pathologist local to your area.

PHI addressed this very topic in their Summer 2010 edition of Post-Polio Health. Read the full article here.

#### **Polio-World Photo Contest**

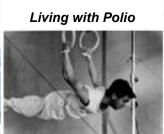


Polio-World is inviting people to send photographs showing their individual history of Polio. They are looking for three photos: the first one to show Polio, the second depicting Living with Polio and the third Adapting to Post-Polio.

Polio-World will use the photographs to create an awareness of post-polio and to show the world that WE ARE STILL HERE!

participate, send your submission mickiminner@msn.com with a description of 50 My name is Charlie, and I live in Tucson, Arizona USA. I got e-mail (see example right), and attach your three photographs. Deadline is September 1, 2011. Be CREATIVE!







Post Polio

Polio

words or less. Please put Polio-World in the polio in 1952 and starting having Post-polio symptoms around subject line, a brief description of yourself in the 1985. I am a retired surgical nurse, and a current glider pilot. Although I don't perform gymnastics anymore, I still haven't let Post-Polio stop me from being active.

#### **Polio Health and Wellness Retreat**

Mt Eliza, Victoria — Thursday 28 April to Sunday 1 May 2011



Polio Australia held its second Health Wellness Retreat at the prestigious Melbourne Business School venue in Mt Eliza, Victoria about 1 hour from central Melbourne. There were participants made up of 43 polio survivors and spouses/carers/ family members. People came from all over Australia except the Northern Territory.

We also had 27 'return' participants who attended last years' Retreat in Baulkham Hills, New South Wales:16 from NSW, 6 from Tasmania and 5 from Victoria, which is testament to how valuable they found the program.

Polio Australia would like to thank all the health professionals and presenters for their valuable time and expertise, most of whom provided their services free of charge. GlaxoSmithKline, The R.E. Ross Foundation and The Ian Potter Foundation funding ensured that this Retreat was as affordable for as many people as possible. Polio Australia is also very grateful to two polio participants who donated money to further subsidise the Registration Fees for eight people who would not have been able to attend otherwise. We also thank the Lions Club of Mentone-Mordialloc for kindly sponsoring Saturday night's entertainment.

Below are a few quotes from those who attended this year:

"We enjoyed the retreat so much. Apart from the excellent presenters, the other 50% of enjoyment came from the friendships and conversations with the other participants—something you can only get from a residential event, being with people who have shared experiences and understand the challenges and triumphs. Thank you sincerely—Joan and Graeme" (polio participant and spouse/carer)

"I would like you to know just how much I enjoyed the weekend at Mt Eliza. For most of my life I just got on with it. Now I am finding the information about polio and the way is has affected me in later years very useful for helping me maintain my independence. Yours sincerely—Fran" (polio participant)

"I just wanted to thank you for the wonderful experience this weekend. I have come away a different person. I met so many amazing people and was privileged to hear parts of their stories. These touched my heart and I came away humbled by the courage, fortitude and positive attitudes that they all had. There was much shared laughter and gratitude for families and supports such as yours. Keep up the great work—Pam" (massage therapist)

Check <u>Polio Australia's website</u> for the 2011 presenters' notes and to learn more about the April 2012 Health and Wellness Retreat being held in Brisbane, Queensland.

# Please pass this e-Bulletin on to friends and colleagues who have an interest in the late effects of polio

- If you are not the original recipient of this e-Bulletin and would like to receive it directly in future, please email us <u>here.</u>
- If you do not wish to receive any further communication from Polio Australia, please email us here.

#### **Polio Australia Incorporated**

PO Box 500 Kew East Vic 3102

Suite 119C, 89 High Street Kew Vic 3101

Telephone: (03) 9016 7678 ♦ Mobile: 0466 718 222

E-mail: office@polioaustralia.org.au ♦ Website: www.polioaustralia.org.au